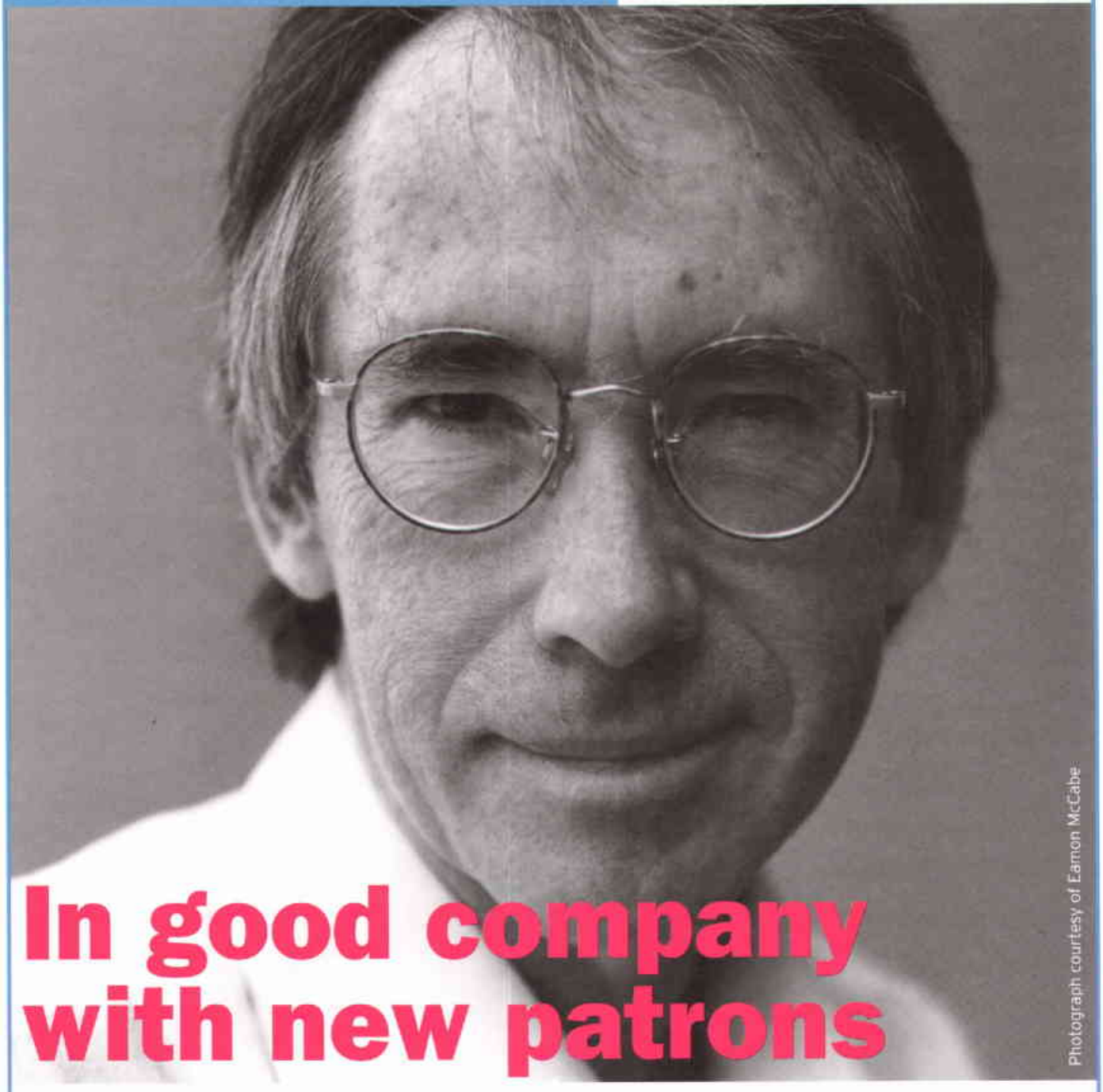
Dignity in dying
your life, your choice

Campaign

for choice, for compassion, for change

Issue 6 Spring 2011



Photograph courtesy of Eamon McCabe

In good company with new patrons

Patrons Reverend Professor Paul Badham • Roy Bailey • Professor Eric Bolton CB • Jo Brand • Chris Broad Rosemary Brown OBE • Carmen Calil • Lesley Close • Jasper Conran • Howard Devoto • Nell Dunn • Sir Terence English KBE FRCS • Brenda Fricker • Professor Anthony Grayling • The Rt Hon Patricia Hewitt • Sir Michael Holroyd CBE • Dame Elisabeth Hoodless DBE • Lord Joel Joffe CBE • Miriam Karlin OBE • Dr Liza Macdonald • Ian McEwan • Dr Ann McPherson CBE • Diana Melly • Rabbi Charles Middleburgh • Sir Jonathan Miller CBE • Deborah Moggach • Dr Michael O'Donnell • Sophie Pandit Sir Terry Pratchett OBE Heather Pratten • Brian Pretty • Nick Ross • Dame Ruth Silver • Sir Patrick Stewart •Janet Suzman Professor Ray Tallis • Zoe Wanamaker CBE • Simon Weston OBE • A.N. Wilson • Matthew Wright

About Dignity in Dying

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Contents

Page 3: Chief Executive
Page 4: Scotland update
Page 5: Patrons
Page 6: Action in Parliament
Page 8: News in brief
Page 10: Supporter spotlight
Page 11: Compassion in Dying update

Who we are

Dignity in Dying is a national campaign and membership organisation. With our 25,000 supporters we work to alleviate suffering at the end of life by campaigning for greater choice, control and access to services.

What we want

We want everyone to have what they consider to be a good death, including the option of an assisted death for terminally ill, mentally competent adults.

We believe that everyone has the right to a dignified death.

This means

Choice over where we die, who is present and our treatment options.

Access to expert information on our options, good quality end-of-life care and support for loved ones and carers.

Control over how we die, our treatment and pain relief, and planning our own death.

What we do

We lobby Parliament, keep assisted dying and end-of-life care in the media spotlight, advise people on their end of life rights, and represent terminally ill people who want the choice of an assisted death by ensuring that their voices are heard.

How you can help

Join us! We are funded entirely by our supporters and are independent of any political, religious or other organisation. If you're not already a member of Dignity in Dying you can join us from as little as £20 per year. Other practical ways to support the campaign can be found in this newsletter or on our website.

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Please note that not all views expressed in Campaign are necessarily those of Dignity in Dying.

Chief Executive

Welcome to Issue 6 of Campaign, whose publication is timed almost perfectly with the first anniversary of the Director of Public Prosecutions' Prosecuting Policy (DPP) on 'Cases of Encouraging or Assisting Suicide'.

As we well know, whilst the prosecuting policy clarified the law on assisting a person to die, it did not change the law, and twelve months on we continue to feel the negative effects of the status quo. In a number of cases, witnesses have already pointed out that the prosecuting policy effectively decriminalises help to die provided compassionately by friends or family, without providing either a means of accessing assisted dying in the UK or any safeguards to protect vulnerable people.

But progress is being made. Demos' Commission on Assisted Dying, chaired by Lord Falconer, aims to explore the mechanisms that could be developed to safeguard vulnerable people, thus potentially enabling an an assisted dying law to make it onto the statute books.

We are also starting to marshall support among newly-elected MPs and newly-enobled Peers. On 1 February we attended the inaugural meeting of the re-constituted All-Party Parliamentary Group on Choice at the End of Life, chaired by new Conservative MP Penny Mordaunt (pages 6 and 7).

Her Vice Chairs are also MPs elected in 2010 - Heidi Alexander (Labour) and Julian Huppert (Lib Dem) - though we retain Officer support from our supportive Peers: Baroness Jay, Baroness Greengross and Lord Joffe.

Media coverage of our new Patrons has been encouraging this year too. In February, Ian McEwan (front cover) appeared in the Saturday Telegraph, joining an ever-growing list of eminent, high-profile supporters including Sir Terrence English, Sir Patrick Stewart, and Sir Terry Pratchett, to name but a few (page 5).

Our charitable partner Compassion in Dying continues to develop and has recently undertaken a thorough research review on the use of Advance Decisions (page 12). We are now able to explore where Advance Decisions are working successfully, where and why they may be failing, and what works needs to be done to ensure that patient choice is respected at the end of life.

Last, but certainly not least, we continue to see the progress made by you our members, as you lobby your MPs, spread the word and try to recruit new supporters. On page 9 you can find some great examples of successful member activism.

I look forward to working with you over the coming year to build on the progress we have made to date.

Sarah Wootton

Mylinh Cao
Press Trainee

Patrick Callaghan
Social Media & Campaigns Trainee

Philip Satherley
Research & Policy Officer

Rachel Watt
Finance Officer

Sarah Wootton
Chief Executive

Tomasz Wlodarczyk
Director of Strategy, Operations & Fundraising

Victoria Holloway
Parliamentary Support Officer

Scotland update

Margo Macdonald MSP's attempts to change the law on assisted dying in Scotland were blocked by a Parliamentary vote in November. Margo shares with us her experience of bringing the Bill and her future plans

"With the upcoming elections to the Scottish Parliament, I can't venture into shops, restaurants, hairdressers' or the various out-patient clinics I attend without someone asking if I'll have another shot at a Bill on assisted dying.

Although gratifying, such authentic information on what people really think can also prove disconcerting if I happen to be bargain hunting in the undies department of a well-known chain store, for example. But no complaints, such encounters are proof that my Assisted Dying Bill enjoyed wide, probably majority, public support, even if MSPs didn't agree. These informal, accidental focus groups confirm the Bill's status as unfinished business, and oblige me to crack on with the Mark 2 version.

Campaigning for the Bill was a bit different from party political or even single issue campaigns like CND or various social policy campaigns like Shelter's Campaign for the Homeless that I've supported for many years. In such eyeball-to-eyeball contests, no holds are barred in winning the point, with the objective of persuading opponents to change sides.

But in advocating assisted dying, I made no attempt to diminish the deep faith that underpinned the religious leaders' objections to the Bill. My campaign for the Bill was of a different stamp to the normal situation of facing political opponents with different views from my own on education or health service provision, for example. Debating the terms of policies like that can recruit or repel support, because the facts surrounding current issues change in a way that does not apply to the constant teachings of churches.

So we didn't run a destructive campaign, even when the Bill's opponents ran a hybrid campaign against "killing" disabled people, old people, chronically sick people. Instead of getting mad, we tried to get even by repeating ad nauseam that our Bill didn't apply to those groups. If I'm re-elected, the Bill I'll introduce will hold to the principle of patient autonomy. However, rather than trying to define categories of condition that would qualify a person to seek help to end a situation they find "intolerable," I'm mulling over the idea of having only one qualifying criterion.

There's a strong attraction in legally defining only one way of enabling someone to seek out professional assistance to bring their life to a peaceful dignified end, as defined by the person concerned. If the qualifying factor was that of being medically diagnosed as being terminally ill, that would surely put to rest the allegations regarding the risk posed by legalising assisted deaths to disabled, old or generally infirm people.

My instinct tells me that if I'm re-elected and produce another Members Bill, the opposition from the sections of the disabled lobby that campaigned against the Bill will not be as vocal against my second Bill. Many campaigners for disabled and vulnerable people know that I, and the public, treat their fears seriously, and ensure that I am alert to the need for precise and unassailable drafting of the Bill's provisions.

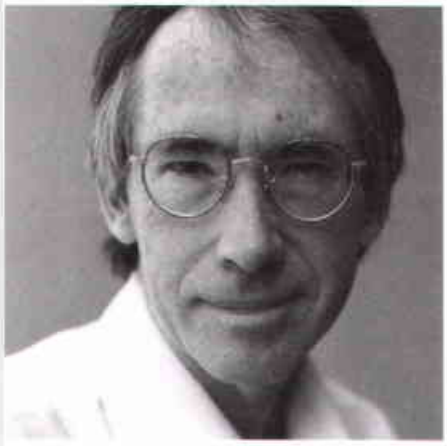
Inevitably, there will be some, perhaps very small, differences in Bills produced for the legal systems north and south of the Border, but good relationships between the campaigns based in Holyrood and Westminster auger well for the whole UK.

Watch this space."

Margo Macdonald MSP

Patrons

Our campaign to legalise assisted dying was given a boost in February when actor Sir Patrick Stewart, former England cricketer Chris Broad (whose wife's death we reported on in the last edition of Campaign) and author Ian McEwan joined our list of high-profile supporters as Dignity in Dying Patrons.



Ian McEwan

"In an interview with the Telegraph, edited for Campaign, Ian McEwan talks about his decision to become a Patron of Dignity in Dying, and what he'd like for his own death.

What really led to it [me becoming a Patron] was my friendship with our GP - a lifetime friend, Ann McPherson. I have known [Ann and] her children all their lives, or a great chunk of it anyway. And she now has pancreatic cancer.

She really is an extraordinary case of an immensely humane woman who has done an enormous amount of work for others. Ann is dying and she is doing it with extraordinary grace and dignity. She has become quite a powerful advocate of this particular cause, not only out of self interest. She has a terminal illness. She would like to have some control of the conditions in which she goes. She is surrounded by a lot of loving family.

But Ann is someone who, because she is so clear and has been a passionate health person all her life, a doctor, it seems to me she is an exemplary case of someone who can teach you how to die, how to do it. That's not to say she isn't terrified like anyone else, or in pain and discomfort and wishing it would all go away, but she has been quite inspirational. That is what has drawn me into the discussion.

I don't think anyone is making a general case for people to be able to have their lives eased away from them in any other condition than having a terminal illness. That's a very important distinction.

Dignity in Dying wants to make a clear separation from the term suicide. Suicide is a colossal act of aggression against the nearest and dearest. It is often carried out in awful conditions of loneliness and desperation. This is different. These are people who are about to die anyway who may well die in great pain, and before they get to that point would rather make a good end surrounded by the people they love.

I would just like to die suddenly of old age while casting for trout on a glorious spring morning. But in the worst circumstances, if I did have an illness like Ann's, then I certainly would like the freedom to be able to go out on my own terms.

I think I know where I would like to be, which would be at home and I would like to be living somewhere in sight of the sublime. I would like a view. I would like a sunset and I would like a river. And I would like family around. I think I would write letters too, farewell letters. Again, assuming I'm not wracked with pain or mental confusion.

It's a painful issue really but finally an enabling one I think."

For a full list of Dignity in Dying Patrons, see the front cover of Campaign or visit our website: **www.dignityindying.org.uk**

Action in Parliament

The All Party Parliamentary Group (APPG) on Choice at the End of Life launched in February with Dignity in Dying as its secretariat. The group's purpose is to promote greater patient choice at the end of life, particularly over where, when and how one dies.

The group believes that mentally competent adults should have the right to refuse treatment and, provided that sufficient legal safeguards are in place, the right to an assisted death. The meeting was extremely successful, with a large number of Parliamentarians in attendance as well as Patrons and Board members of Dignity in Dying. We welcome the formation of the group and congratulate Penny Mordaunt MP on her election as Chairman, along with her colleagues and peers from all the parties who have taken Officer and Qualifying Member positions.

The meeting was addressed by Dr Ann McPherson CBE, Chair of Healthcare Professionals for Assisted Dying (HPAD). She outlined the development of HPAD and explained that its role is to ensure that the voices of healthcare professionals in favour of assisted dying are heard. She said that HPAD's almost 400 members are committed to both supporting palliative care and allowing terminally ill, mentally competent adults the choice of an assisted death. She also discussed the urgent need for a change in the law on assisted dying following the Director of Public Prosecution's new prosecuting policy, which has effectively decriminalised compassionate amateur assistance to die.

Chair of the APPG on Choice at the End of Life and Conservative MP for Portsmouth North, Penny Mordaunt, said: "Choice at the end of life is one of the key issues of our time, and one that needs to be urgently addressed by Parliament. I am delighted to be working with colleagues from across the political spectrum on increasing choice for dying adults. I know from the letters and emails I have received from my constituents, and from polling that was conducted by my local newspaper, that this is an issue that people feel very strongly about."

Penny Mordaunt, MP

Sarah Wootton, Chief Executive of Dignity in Dying, said: "The creation of the APPG on Choice at the End of Life is an important step forward in the campaign to increase choice for dying adults. It is hugely encouraging that this group has the support of such well-respected Parliamentarians from across the political parties. I have no doubt that a change in the law to allow the choice of assisted dying to terminally ill mentally competent adults is not far away, alongside improving other aspects of patient choice at the end of life."

The group will now seek to build support in Parliament for a considered and well-drafted Bill, which would provide clarity and resolute safeguards for those who wish to have an assisted death.

How to contact your MP

Find out who your MP is and get their contact details by visiting www.writetothem.com or by phoning the House of Commons Information Office on 020 7219 4272.

Face to face meetings are often far more successful than letter-writing and you can usually meet with your MP at a local surgery or by making an appointment. To schedule a meeting you should call your MP's Westminster office on 020 7219 3000.

Alternatively, write to your MP at:

House of Commons, London, SW1A 0AA

Or email them through www.writetothem.com

ACTION! ASK YOUR MP TO JOIN THE APPG ON CHOICE AT THE END OF LIFE

1. If your MP is an Officer or Qualifying Member of the APPG on Choice at the End of Life (see below) we urge you to get in touch to thank them for their support; no doubt they will receive some critical correspondence so we need to make sure that they receive positive letters on the great work they are doing.
2. If your MP is not already a member of the APPG, you might ask them to consider joining. If they feel unable to do this, would they like to receive updates on the group's activities?
3. The APPG is not for MPs alone to join, so if you know any members of the House of Lords please contact them and ask them to join too.

Officers

Penny Mordaunt MP - Conservative, Portsmouth North

Heidi Alexander MP - Labour, Lewisham East

Julian Huppert MP - Liberal Democrat, Cambridge

Dr Caroline Lucas MP - Green, Brighton, Pavilion

Qualifying Members

Karen Lumley MP - Conservative, Redditch

Brandon Lewis MP - Conservative, Great Yarmouth

Richard Ottaway MP - Conservative, Croydon South

Gavin Barwell MP - Conservative, Croydon Central

Richard Graham MP - Conservative, Gloucester

Anne-Marie Morris MP - Conservative, Newton Abbott

Andrew George MP - Liberal Democrat, St Ives and the Isle of Scilly.

Kerry McCarthy MP - Labour, Bristol East

David Winnick MP - Labour, Walsall North

Please make your letter as personal as possible; MPs are inundated with standardised responses and the more your letter or email is about your own views and experiences the more likely it will be to make an impression. Even better, if you feel able to meet your MP at their surgery, it is certainly the most effective way to influence their opinion.

Further points you could make:

This year marks the 50th Anniversary of the 1961 Suicide Act. This is a law which does not distinguish between compassionate assistance to die for people in the last days and weeks of their life and malicious or irresponsible assisted suicide for people who are not dying.

MPs may view this as a contentious issue, but it is important to reinforce the overwhelming public support for change, with British Social Attitudes surveys consistently showing support at around 80%.

The Director of Public Prosecutions guidelines are helpful in clarifying the law, but Parliament must ultimately determine who should and should not be prosecuted for helping someone to die.

Please keep us updated on your progress and forward any correspondence you receive when you can.

News in brief

Baroness Warnock gives evidence to Commission on Assisted Dying

Baroness Mary Warnock

Baroness Mary Warnock gave evidence to the Commission on 19 January. She said that the current law is unsustainable as it lumps together assisted suicide enthusiasts and compassionate assisters of a loved one. Baroness Warnock told Commissioners: "I believe that there is a very large number of people who don't have that good death; who have a bad death. And I think that's a moral issue that society has got to face."

Sarah Wootton, Dignity in Dying's Chief Executive, also gave evidence to the Commission. She spoke of the problems with the current law and the Director of Public Prosecution's Guidelines; clarified Dignity in Dying's proposed legislation as applicable only to terminally ill mentally competent patients, within safeguards; and used the experience of Oregon in the United States to give an evidence-based answer to the Commission's questions.

Health Ombudsman's damning report reveals NHS failing older people

In February Ann Abraham, the UK Parliamentary and Health Service Ombudsman, released a report that catalogued an array of failings in hospitals and GPs' surgeries. The report focused on ten patients in particular, who were left to suffer unnecessary pain, indignity and distress in their end-of-life care. The main failings towards (generally older) people at the end-of-life were of dehydration, poor nutrition, inadequate pain relief, badly managed medication and poor communication with their attending healthcare professionals. There was widespread coverage of the report in the national press.

NHS chief backs calls to reform assisted dying law

In late February Pauline Smith, Chief of the West Midlands NHS Strategic Health Authority, switched from a position of opposition to one of neutrality on the issue of assisted dying. Her reasons for doing so were both to encourage debate on the issue among healthcare professionals and to address the problem of misrepresented (lack of) support for assisted dying among healthcare professionals and health colleges. While roughly 50% of doctors, and a higher proportion of nurses, are in support of assisted dying, most healthcare colleges' official positions are in opposition. Ms Smith herself is in support of assisted dying and, giving evidence to the Commission on Assisted Dying, stated that the current law is unsatisfactory because only patients who can afford to go to Switzerland have choice over how they die.

Channel 4 TV, Dispatches Documentary: NHS Secret Diaries

At the end of February, Channel 4 broadcast a Dispatches feature "NHS Secret Diaries". This hour-long documentary followed three patients through their end-of-life care; one in a hospital, one in a hospice, and one at home. The patients' frustrations and struggles in obtaining access to palliative and other end-of-life care made for upsetting viewing, but nevertheless the programme highlighted gaps in NHS end-of-life care and sensitively documented the patients' dying days. The programme also highlighted the gulf between patient expectation and wishes, and the reality of their end-of-life experience: for example, while 60% of people would prefer to die at home, only 18% actually do.

Oregon figures show no increase in numbers

In January, the US state of Oregon published its 2010 report on assisted dying, which has been legal for terminally ill mentally competent adults since the 1997 Death with

Dignity Act. The report showed that there have been no significant changes in the numbers of assisted deaths, or the reasons patients stated for choosing an assisted death since 2009. 65 people were assisted to die in Oregon in 2010, and this accounted for 0.2% of total deaths in Oregon. The report also showed that an overwhelming majority of those assisted died at home and were enrolled in palliative care services.

There have been several developments to the Dignity in Dying staff team over the last few months. Here two of our most recent additions tell us why they joined the organisation and what they hope to bring to the campaign.

Anna Boehm joined Dignity in Dying's policy team in February as our Policy Support Officer. She comes to Dignity in Dying from Parliament where she worked for three years as a policy researcher for an MP. Anna has a degree in Social Anthropology and has worked on a number of independent research projects. Anna helps devise and deliver Dignity in Dying's policy and legal strategy work and can be contacted for advice on all things policy related.

Anna told Campaign: "I've believed assisted dying should be legalised since a Religious Education lesson when I was a teenager - the first time I really considered it! I believe coerced suffering is wrong and that the sort of legal and ethical fudge currently surrounding assisted dying is unhelpful and morally feeble. It's a privilege to work for Dignity in Dying on a campaign I am so committed to seeing succeed."

Victoria Holloway started as Parliamentary Support Officer to Dignity in Dying in January. Skilled in parliamentary and Government relations and an experienced campaigner, Victoria's previous experience includes Parliamentary Researcher and Caseworker for two MPs; working within the policy and communications department of a trade union; and Government Relations Assistant at a large mental health charity. Victoria is responsible for helping to co-ordinate our parliamentary activity and is the first point of contact for supporters on these issues.

On joining Dignity in Dying Victoria said: "I have been involved in politics since I was very young and my political background has made me want to help bring about real change that improves people's lives. This is a campaign that's worth fighting for. The law currently is not fit for purpose and needs to be changed in line with what people want in the 21st century."

And finally...

Jen Hardy, our much valued Campaigns Support Officer, left Dignity in Dying in January to pursue her dream of travelling the world. Jen was an invaluable team member for over two years and will be sorely missed.

During her time here Jen successfully developed our Party Conference Fringe events, organised many speaking events throughout the UK, coordinated our Parliamentary activity, was a constant source of support and guidance to Dignity in Dying supporters, and was a very friendly and enthusiastic member of the team. We wish her very well and thank her for all her hard work.

Supporter spotlight

With 25,000 supporters across the UK, we are frequently overwhelmed by the tireless campaigning work you do to help progress our campaign to change the law on assisted dying. Without your activism and support, we would not be where we are today. Here we share some recent efforts and ideas on ways we can help you become more active as a supporter.

LOBBYING MPS

Colin and Dorothy Graham from Canterbury have been busy lobbying MPs who expressed support for Baroness Campbell's Resistance Charter, which asks MPs to oppose any attempts to change the law on assisted dying. As members of the Liberal Democrat Party, along with writing to their own MP, they also wrote to all seven Liberal Democrat MPs listed as supportive of the Resistance Charter's aims - one of whom promptly disassociated himself from the campaign.

How we can help

If you are in contact with your MP and come up against difficult questions or responses, get in touch. We can help prepare letters in reply, send policy briefings on specific areas of concern, or provide new ideas on ways to engage your MP. Contact Victoria at victoria.holloway@dignityindying.org.uk or on 020 7479 7109.

RECRUITING NEW MEMBERS

Dignity in Dying member John Sibley from Dentdale has been spreading the word of our campaign and trying to recruit friends and family members as supporters by ordering copies of our membership leaflets and newsletters to get conversations started on the subject.

How we can help

We have 'Join us' membership leaflets and freepost envelopes which you can use to gain new members. We also have freepost 'find out more' postcards that interested people can return for more information. Contact Ian to order copies of either on ian.walker@dignityindying.org.uk or on 020 7479 7730.

SPEAKING EVENTS

Steve Barksby from Manchester has been speaking about assisted dying at various schools in the North West in various ethics, religion and philosophy-based classes. Dignity in Dying Board member Niccola Swan also spoke to a local Humanists' group in Hull.

How we can help

We can provide speakers for events across the UK. Alternatively, if you are interested in speaking to a local group on behalf of our campaign, we can supply you with materials and template presentations. Contact Anna at anna.boehm@dignityindying.org.uk or on 020 7479 7730.

WORKING WITH LOCAL NEWSPAPERS

After submitting evidence to the Commission on Assisted Dying, Bill Hill responded to a negative article on assisted dying in his local newspaper, the Leicester Mercury. Along with rebutting the points made in the article, he also used this as an opportunity to promote the Commission and encourage readers to get involved with the debate by submitting evidence.

How we can help

We can find the name and address of your local newspaper editor and advise you on what to include in your letter. Contact Jo at jo.cartwright@dignityindying.org.uk or on 020 7479 7737.

SPREADING THE WORD

Jill Winter emailed twenty of her friends with a copy of our mini newsletter on the Commission on Assisted Dying asking them all to take time to submit their views to the Commission.

How we can help

We can send additional copies of any Dignity in Dying publication for you to share with friends. If you would like additional copies of any issues of our newsletter contact Emily at emily.halsall@dignityindying.org.uk or on 020 7479 7732.

Compassion in dying update

Compassion in Dying, established by Dignity in Dying in 2007, supports people at the end of life to have what they consider to be a good death by providing advice and information around their rights and choices. Here we get an update from our charitable partner.

With the Health and Social Care Bill being described as the "biggest shake up of the NHS in 60 years" Compassion in Dying has been following the Bill closely to ask, how will it affect end-of-life care?

The Health and Social Care Bill is making its way through Parliament and has attracted the attention of many national charities, all wondering how the NHS reforms will affect their area of work.

The Health and Social Care Bill aims to:

- Increase integration of health and social care.
- Bring healthcare commissioning closer to patients by dissolving Strategic Health Authorities (SHAs) and Primary Care Trusts (PCTs), and creating an NHS Commissioning Board and GP commissioning consortia who will commission healthcare services.
- Increase public involvement in local healthcare decisions by setting up local HealthWatch groups.

This could improve end-of-life care by making sure the NHS and local services work together more effectively, but there are concerns about whether the Bill, as it stands, will be able to deliver on these aims and that end-of-life care will lose out to competing priorities.

We are concerned that the Health and Social Care Bill does not place enough emphasis on end-of-life care, but Compassion in Dying believes changes to the Bill could make it have positive effects on end-of-life care provision.

We will be following the Bill's progress closely and will keep you updated.

Care Quality Commission publishes guide for all those receiving care

At the end of February the Care Quality Commission (CQC published two new guides for people who receive care in a care home or in their own home in England. The guides tell you about what you can expect from your care service, and what to do if you need to make a complaint.

They also contain information on changes to the way care is regulated, which mean services must now meet new standards The guides are available on the CQC website at www.cqc.org uk, or you can contact the CQC for more information on 03000 616161.

Jo Thomas

Charity Development Officer

Compassion in Dying is a charity that supports individuals at the end of life to have what they consider to be a good death.

We provide information and support around patient rights and options, and conduct research into end-of-life issues.

Chair: Rowena Ironside

Chief Executive: Sarah Wootton

Address:
181 Oxford Street, London W1D 2JT

Email: info@compassionindying.org.uk

Telephone: 020 7479 7731

Website: www.compassionindying.org.uk

NEW! Find us on facebook

Compassion in dying update

Research and Policy Officer, Philip Satherley, updates us on some recent developments in Compassion in Dying's work to support patient choice at the end of life.

What is your role at Compassion in Dying?

I work both for Dignity in Dying and Compassion in Dying and whilst my work at Dignity in Dying is focused on extending people's choices at the end of life, Compassion in Dying works to support existing rights under UK law. My main role for the charity is to conduct research and keep up-to-date with developments in end-of-life care issues such as the use of Advance Decisions.

What is Compassion in Dying working on at the moment?

One of the main things Compassion in Dying does is provide free Advance Decisions, so we decided to conduct a systematic review (a scientifically structured literature review) of all the research that looks at whether the choices set out in Advance Decisions (such as Do Not Attempt Resuscitation and refusal of antibiotics) are respected by healthcare professionals.

No other organisation had examined all of this research evidence and we felt it was vital to demonstrate where Advance Decisions (and other formal processes to nominate a trusted person to make decisions for you such as Lasting Power of Attorneys) are working or failing. Unfortunately we found no research from the UK which has examined whether Advance Decisions are followed, however, we now know that they are being used successfully in the USA. This is not to say that your wishes won't be respected over here, but simply that no research has been done. This needs to be addressed and we believe stronger systems need to be in place to enable doctors and other healthcare practitioners to access your Advance Decision or Lasting Power of Attorney (LPA).

What are Compassion in Dying's plans for the next 12 months?

Using evidence from the review, we are developing Compassion in Dying's research plans for the future and we are working alongside other charities and, hopefully, Government to examine how we can make sure Advance Decisions and LPAs work.

A copy of the review will be available on the Compassion in Dying website at the end of March and we hope to publish articles in a number of healthcare journals. We are also working to establish an Information Line on end-of-life care - look out for more in this in the next edition of Campaign.

WAYS TO GIVE TO COMPASSION IN DYING

Number 1: Legacies

In each edition of Campaign, we will feature a different way to donate to Compassion in Dying. As a registered charity, there are lots of ways that you can give. In this edition we focus on Legacies.

For many people a Legacy is the most significant charitable gift of their life. Without the Gifts which our supporters have made in their Wills, Compassion in Dying would not have been able to provide Advance Decisions for free, develop our research programme, or create a more accessible website.

I am thinking of making a Gift in my Will to either Dignity in Dying or Compassion in Dying. Who should I choose?

Your decision will depend on what is most important to you.

If you would like your legacy to be used to help change the law on assisted dying, then choose Dignity in Dying.

If you would like your legacy to work more broadly, helping others achieve a "good death" through information and empowerment around their end-of-life choices, choose Compassion in Dying. There are also tax benefits associated with leaving a legacy to Compassion in Dying, because of its charitable status.

If you would like more information on Gifts or Legacies, please call Tomasz on 07962 414 900.